

Procedural pain management in Italy: learning from a nationwide survey involving centers of the Italian Association of Pediatric Hematology-Oncology

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Abstract

Procedural pain is an important aspect of care in pediatrics, and particularly in pediatric oncology where children often consider this to be the most painful experience during their illness. Best recommended practice to control procedural pain includes both sedative-analgesic administration and non-pharmacological treatments, practiced in an adequate and pleasant setting by skilled staff. A nationwide survey has been conducted among the Italian Centers of Pediatric Hematology-Oncology to register operators' awareness on procedural pain, state of the art procedural pain management, operators' opinions about pain control in their center, and possible barriers impeding sedation-analgesia administration. Based on indications in the literature, we discuss the results of the survey to highlight critical issues and suggest future directions for improvement. Future objectives will be to overcome differences depending on size, improve operators' beliefs about the complexity of pain experience, and promote a global approach to procedural pain.

Introduction

Pediatric patients often refer to invasive procedures as the most painful episodes they experienced during the course of their malignancy.¹ In addition to pain provoked by the invasiveness of each procedure, procedures can also generate distress and anticipatory anxiety.² Anxiety and distress can generate negative feedback that worsens the children's procedure-related experiences and increases their perceived pain.^{3,4} Moreover, pain, partic-

ularly if recurrent or repeated, could generate behavioral changes, such as a loss of appetite, sleeping difficulties, regression, and aggressiveness.⁵ Studies have also suggested a correlation between childhood pain and fear of medical procedures, sensitivity to pain, and fear and avoidance of health care in adulthood.⁶

*The ideal goal of pain management for pediatric procedures is to make the procedures comfortable for the child and his or her parents,*⁷ general principles were provided in 1990 (Table 1). To date, several international guidelines have been produced in America and Europe.^{8,9} Nevertheless, research has failed to provide a global picture of the current application of guidelines in practice.^{10,11}

In 2010, we developed a nationwide survey among centers belonging to the Italian Association of Pediatric Hematology Oncology (AIEOP) to describe state of the art procedural pain management for cancer children in Italy. We developed a 2-part questionnaire: part A, intended for the Director of each AIEOP center, containing questions about procedural pain management (e.g. staff, setting, use of sedation-analgesia, monitoring) and part B, intended for all the physicians, nurses, and psychologists employed in each center. They were asked to give an assessment of the pain experienced during these procedures, to evaluate the quality of pain control in their center and to indicate the importance of various factors in the choice of performing the procedures without sedation-analgesia. The procedures we asked about were lumbar puncture and bone marrow aspiration and biopsy, frequently performed in treatment protocols for children with leukemia and lymphoma. Results obtained provide a global overview of procedural pain management for children with cancer in Italy (Figure 1). Based on a literature review, we delineate critical issues and future directions to improve this aspect of care.

Awareness of procedure pain among the operators involved

It had been demonstrated that the beliefs of healthcare providers influence the number of interventions performed in order to control children's pain.¹² Invasive diagnostic-therapeutic procedures are considered painful by all the caregivers involved: scores were assigned according to how painful the procedures were on a scale of 0-10. These exceeded score 5 in 77.2% for the lumbar puncture, 97.5% for the bone marrow aspirate, 99.5% for the bone marrow biopsy. A priori opinions about pain depend on invasiveness of the procedure. The professional role is another factor which influences a priori opinions.

We found a significant difference (5%) concerning lumbar puncture and bone marrow aspirate between the rates of painfulness of nurses and those of physicians. Nurses tended

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Key words: procedural pain, pediatric oncology, pain management, sedation-analgesia

Conflict of interest: the authors report no conflicts of interest.

Received for publication: 6 October 2011.

Accepted for publication: 24 October 2011.

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Pediatric Reports 2011; 3:e34
doi:10.4081/pr.2011.e34

to attribute a higher score to pain. No significant differences were seen regarding bone marrow biopsy; this confirms that invasiveness influences the perceived painfulness of the procedure.

Adherence to recommendations about procedural pain management

Children's and parents' involvement.

The parents' role is essential both in developing coping strategies and in experiencing distress during the treatments.¹³ Parental expectancy about painfulness of the procedures was found to influence the relationship between children's expected and experienced pain during lumbar puncture.¹⁴

When informed consent is requested from parents before the procedure, information is usually provided about the development of the procedure, the opportunity of sedation-analgesia and the risks involved. This could also be considered the moment to suggest practical indications to help their child cope with fear and anxiety during the procedure. Although we found parents involved through the presentation of an informed consent in all the centers (100%), they could only stay with their children during the induction of sedation-analgesia in 82% of the centers. In all the centers where parents cannot assist in the induction of sedation-analgesia, procedures are carried out in the operating theater.

Careful treatment during the first procedure

The experience of the first procedure plays an important role in the development of anticipatory anxiety and fear during subsequent procedures, worsening the quality of life of children and parents. This is why a maximal treatment for pain and anxiety had been rec-

ommended for the first procedure at diagnosis.⁷ Sedation-analgesia is provided most frequently when a child is subjected to a procedure for the first time compared with subsequent procedures (*almost always* 86.2% vs 84.2%). Nevertheless, children's response to a stressful event such as an invasive procedure is individual and could vary between procedures depending on the circumstances. A

child's perception of the invasiveness of a procedure and the related painful experience are not necessarily proportional to the invasiveness perceived by the operator. Anxiety, distress and pain perception cannot be predicted in advance. As a consequence, all available means to control pain and anxiety should always be used.

Comprehensive use of pharmacological and non-pharmacological treatments

The best method to control procedural pain includes: i) combination of analgesics and sedatives; ii) anxiety control to avoid *fear of treatment*.⁷

Sedation-analgesia is *almost always* provided in about 85% of centers. One center (2.7%) used only local anesthesia for all the procedures and "rarely" sedation-analgesia (it has about 30 new diagnoses each year).

Non-pharmacological treatments are used in 55.5% of the centers, mainly by psychologists (60%). Only in 3 centers (8%) are physicians, nurses, and psychologists involved together. Centers where these treatments are used perform a greater number of procedures than the others (mean 540 vs 269 procedures/year). Sixty-eight percent of the centers which do not use any non-pharmacological treatment perform almost one of the three procedures in the operating theater.

Overall, 28% of the centers *almost always* had a comprehensive approach with sedation-analgesia and non-pharmacological treatments. Among these centers, only one performs less than 200 new procedures/year; others range from 236 to 1,500.

Safe administration of sedation-analgesia

Patient monitoring depends on each center. Recommended monitoring indicated by the international guidelines (continuous peripheral oxygen saturation, heart rate, respiratory rate and blood pressure before and after the induction of sedation, during the procedure and at discharge)⁸ is performed in 15 centers (42%). Adequate monitoring is more likely when procedures are carried out in the operating theater compared with other settings (60% vs. 40%). The 25.7% of children are discharged from the procedure room before fully waking up. Waking up is one of the most critical phases of sedation-analgesia, because patients may still be in a state of relative sedation.¹⁵ It is, therefore, necessary to closely continue monitoring at this stage.

Adequate skills for staff involved

The presence of trained staff devoted only to sedation-analgesia and not involved in the procedures is required by the international guidelines to assure a safe sedation. Staff performing the procedure were not the same as the staff providing the sedation-analgesia in 94%. Sedation analgesia is performed by *oncologists* at 2 centers (5.5%); both perform less than 200 procedures each year.

Other centers employ *anesthetists* (83.3%), *pediatricians with anesthesiological training* (5.5%), *residents supervised by an expert physician* (5.5%). The work overload in the anesthesia services may, therefore, explain the number of procedures performed without sedation-analgesia.⁹ The solution in many countries is

Table 1. Recommendations for procedural pain management produced in 1990 by the subcommittee on management of pain associated with procedures in children.

General principles of medical procedure for the management of pain and anxiety

1. Preparation of child and parents with specific roles for parent(s).
2. Maximum treatment of pain and anxiety for the initial procedure to reduce the development of subsequent anticipatory anxiety symptoms.
3. Adequate knowledge of behavioral and pharmacological treatment of acute pain and anxiety by medical staff responsible for medical procedures.
4. Appropriate *monitoring and resuscitation equipment* in the procedure room.
5. Adequate *mechanical skill in individuals* who plan to perform pediatric procedures.
6. Ongoing *evaluation of the child* to assess efficacy of treatment for pain and anxiety.
7. Creation of as pleasant an environment as possible in the treatment room.

Part A: 36 on 54 Centers (66.7%)



Part B: 24 on 54 Centers (44.4%)
248 nurses, 120 physicians, 22 psychologists



Figure 1. Participation in our survey conducted in 2010 among Centers of the Italian Association of Pediatric Hematology-Oncology (red starlets=responders; black starlets=non responders).

Table 2. Good aspects in procedural pain management emerging from our survey and recommendations for improvement.

Positive issues	Recommendations for improvement
Sedation-analgesia <i>almost always</i> : 85% of the centers.	Provide recommendations and suggestions for small center organization of adequate services
Careful treatment for the first procedure	Provide indications to create adequate setting both for safe and pleasant sedations
Dedicated and skilled staff	Introduce training in sedation-analgesia during the pediatric residency
Monitoring of vital signs:100%	Educate healthcare providers about complexity of pain experience in children, the best comprehensive approach, the need for re-evaluation of pain after treatment
Parent involvement: informed consent (100%) presence during the induction of S/A (82%)	Improve nurses' role in the care of children submitted to painful procedures

that non-anesthetists are trained to provide sedation-analgesia.¹⁶ Operating in an adequate setting they can assure a safe use of sedation-analgesia.¹⁷

Efficacy assessment

Only 13 centers (36%) reported that they asked children to give an assessment of the pain experienced after the procedures, and even less during the procedure (22%). Efficacy assessment through self-reported or observational pain scoring is recommended.⁷

Pleasant environment

Approximately 50% used the operating theater as the usual setting. One center performs the procedures at the patient bedside (2.7%). Environmental and psychological factors are more likely to influence pain and anxiety in children than in adults.⁵ The operating theater guarantees a safe environment; however, studies comparing general anesthesia in the operating theater and sedation for procedures in children have demonstrated that the latter was preferred by patients because it entailed an earlier discharge, a more familiar environment, and it also allowed the parents to stay close to the child.^{18,19} All these can reduce a child's anxiety and pain. Several studies demonstrated that an adequately equipped setting with a skilled team can assure safe and efficacious sedation also outside the operating theater. Moreover, according to the international guidelines, sedation-analgesia at the patient's bedside should be avoided to maintain the concept that this is a safe *nest*.

Perceived barriers to sedation-analgesia administration and operators' opinions about procedural pain control

Pain management is generally considered good (mean approximately 8 on a 0-10 scale). Nurses tended to attribute lower values than physicians and psychologists (mean 7.8 *vs* 8.4 and 8.3, respectively).

Among all responders, 60% of the nurses, 59% of the physicians, and 77% of the psychologists indicated the causes related to performing the procedures without analgesia. The first relevant factor was the lack of ability of the dedicated staff to manage sedation-analgesia (relevant for 86% of nurses, 87% of physicians, 70% of psychologists). This factor received the highest score over all categories.

The second most important reason was the doubts about the safety of sedation-analgesia (relevant for 65% of nurses) followed by the lack of space and equipment (relevant for 68% of the physicians).

A range of critical issues were identified, including the fact that a comprehensive method was not always used, a dedicated team was not always available, and the limited practice of non-pharmacological treatments, etc.

Most of these issues concern centers with less than 200 procedures each year. Centers that perform a greater number of procedures each year were more likely to have an organized setting for all the procedures and they could employ a skilled dedicated team. When settings other than the operating theater are used, adequate monitoring during and after the procedure is less likely. On the contrary, when procedures are carried out in the operating theater, usually parents cannot stay with their children during the induction of sedation-analgesia. The setting used should not influence adherence to the international guidelines, maintaining safety of sedation and also gaining control of patient's fear and anxiety. Lack of staff is globally considered an important barrier to administration of sedation-analgesia. According to our results, anesthetists provide most procedural sedation-analgesia for cancer children in Italy. Non-anesthetist sedation-analgesia could be adopted in the near future in Italy, especially at teaching hospitals, as part of standard training for pediatricians.

The last barrier to a comprehensive procedural pain treatment is that procedural pain is attributed mainly to procedure invasiveness. All stake-holders need to be educated about the complexity of the pain experience in children, and about all means available to treat fear, anxiety and pain, and about the need for re-evaluation of pain after treatments.

Operator distress could become a further barrier to complete pain treatment. In fact, distress as experienced by patients and nurses is positively correlated.²⁰ Nurses seem to be more concerned about children's experience, because they tend to attribute higher pain values to the procedures and lower values to pain control. Since nurses feel better when children's symptoms are well-controlled and the amount of action they can take on pediatric symptoms positively influence their levels of distress,²¹ they should be actively involved before, during and after the procedure also in the relationship with the patient, providing adequate time input and maintaining their role of care.

Conclusions

Data from our survey give us a picture, albeit incomplete, of the management of procedural pain in most centers of pediatric Hematology-Oncology in Italy. Future objectives will be to overcome the differences in the procedural pain treatment between the Italian centers, which appear to be dependent on size, to improve operators' beliefs about the complexity of pain experience, and to promote a global approach to procedural pain, including pharmacological and

non-pharmacological treatments (Table 2). The international guidelines should be targeted on single-center resources, promoting a wider diffusion of general indications. These will concern: i) a duty to perform a re-assessment of pain after treatment; ii) the physiological-pathological rationale for the use of non-pharmacological treatments, especially if the procedure is carried out in the operating theater; and iii) the importance of careful monitoring regardless of setting.

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